

MEMORANDUM
DEPARTMENT OF COMMUNITY HEALTH
LANSING, MICHIGAN 48909-7979

DATE: June 2005
TO: Families of Children with Special Needs
FROM: Mary Marin, Executive Director, Parent Participation Program (PPP)
Children's Special Health Care Services (CSHCS) Division
SUBJECT: Heart-to-Heart Information Updates

Best wishes to Linda Yellan, RN. She is retiring in July after many years in the Ingham County Health Department's CSHCS office. She is a member of the CSHCS ad hoc committee that grapples with local health department issues and has served in other CSHCS advisory roles.

As a reminder, several CSHCS information items are available:

- CSHCS *Family Guide* – the new, 48-page booklet that explains our program
- CSHCS poster -- an old but useful full-color 16" x 20" page that lists services
- "Packaging Wisdom" -- a family booklet for recording details of a child's special needs

To make a request, families may call Leah on our CSHCS Family Phone Line at 1-800-359-3722.

Professionals may call her at (313) 456-4381. Or, email to waterslea@michigan.gov.♥

Watch your mailbox this month for our conference brochure on "Relatively Speaking." Our Nov. 4-6 event in Grand Rapids focuses on issues of siblings of children with special needs.

PPP Update

Michigan **families of children with metabolic conditions** may tap seven moms for parent support. Each has a child whose condition was discovered through newborn screening (NBS). The conditions of their children include galactosemia, Maple Syrup Urine Disease (MSUD), and phenylketonuria (PKU). The children's ages range from under one to 14. Six of the moms completed *Family Support Network of Michigan* support parent training tailored for them last fall. They are Annette Armentrout, Cheryl Mac Vicar, Denise Pinskey, Paula Ruter, Kathy Streng and Becky Weber. Sandy LaPrad, lead parent consultant for NBS, completed

the training earlier. Families may reach any of them toll-free by dialing the CSHCS Family Phone Line (1-800-359-3722) and asking to be transferred to a NBS support parent.♥

The **CSHCS Family Guide** is a good to excellent resource, according to 17 of 23 report cards received since March. A Wayne County parent wrote "Keep up the good works, the material is very helpful, as we have three with CSHCS in our family."

Four parents ranked the book's ease of reading as average to failed. Most of them cited light ink -- caused by a production problem.

In all, PPP has received 166 report cards since the book was distributed in December. More than 80 percent of

readers gave the guide "A"s (excellent) or "B"s (good) in all categories.♥

CSHCS Update

CSHCS members with private insurance will receive a letter soon explaining that if they have a mail order pharmacy benefit, they must use it. When the change takes place, CSHCS no longer will pay for prescriptions filled at local pharmacies that mail-order benefits cover. If a co-pay is required, CSHCS will pay it.

The letter will detail the CSHCS procedure for using mail-order pharmacies. For questions, families may phone the Beneficiary Helpline toll-free at 1-800-642-3195.♥

Events

Braille Beats, a residential fine arts program for youngsters who are visually impaired, takes place **Aug. 14-21** at Lions Bear Lake Camp, **north of Lapeer**. Sponsor is *Blind Vision*. Request a registration packet from Susan Gardner at (248) 684-2796 or braillebeats@yahoo.com or from Brunhilde Merk-Adam at (248) 727-2260 or bkmabma@worldnet.att.net. ♥

A two-day Sibshop Training is set for **Sept. 9-10** in Detroit. It is part of Children's Hospital of Michigan's 8th annual *Issues and Challenges* conference. Featured speaker is Don Meyer, director of the Sibling Support Project of the Arc of the United States. "Tuition assistance" is available to families. Babysitting is available for a limited number of pre-registered children. For details, phone (313) 745-5458 or email to sboyd2@dmc.org. ♥

Resources

The Youthhood (www.youthhood.org) is an interactive, dynamic new site that young adults with special needs and their parents can use to plan for life after high school. "Youthhood offers a unique and extensive blend of content, interactive activities, links to related Web sites, and planning tools," states the host, the *National Center on Secondary Education and*

Transition. "The site provides a progressive learning experience ... the more activities that are tried and planning that is done, the more youth will learn and be able to apply the information to their own lives."

Youthhood is organized like a neighborhood. Among seven locations, **The Health Clinic** addresses managing care and preventing problems. It also covers disabilities and chronic illness, insurance, relationships, and sexuality. ♥

The Michigan Yellow Pages for Kids with Disabilities is an online resource for families. The publisher, Wrightslaw, lists educational consultants, psychologists, diagnosticians, health care specialists, speech language therapists, and more. The address is www.yellowpagesforkids.com/help/mi.htm. ♥

Southeast Michiganders who are deaf or blind may apply to the **Elizabeth Wight Fund for "direct assistance" grants**. Applicants must live in Oakland, Livingston, Macomb, Monroe, St. Clair, Washtenaw or Wayne County. The grant may provide assistive technology, personal equipment, supplies or services to make the individual's life easier. For details reach Cassandra Joubert at the *Community Foundation for Southeastern Michigan* at (313) 961-6675 or cjoubert@cfsem.org. ♥

Dose of Humor

From the Kid's Guide to Life

From Andrew, 9: "Never smart off to a teacher whose eyes and ears are twitching."

The Parent Participation Program (PPP) is a section of the Children's Special Health Care Services Division (CSHCS) of the Michigan Department of Community Health (MDCH).

CSHCS is part of MDCH's Bureau of Children and Family Programs. CSHCS primarily provides medical specialty care to children with a qualifying diagnosis. PPP serves families of all children with special needs. The Family Support Network of Michigan (FSN) is PPP's parent-to-parent support arm.

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CSHCS Family Phone Line
1-800-359-3722
8 a.m.-5 p.m., Monday – Friday

CSHCS and this memo online
www.michigan.gov/cshcs

Free online course on CSHCS
www.training.mihealth.org

Events and Resources are compiled by PPP from a variety of sources. A listing does not denote endorsement.

If you receive multiple copies of this memo by mail, please let us know. To add your name to our postal mailing list or to remove it, families may call our Family Phone Line. Others, please phone (313) 456-4381.